



The love of a father who dedicated 12 years of his life to caring for his daughter.

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Driving through country lanes on my way to Midhurst, West Sussex, I wondered how my interview with Malcolm Blair Robinson would go. Malcolm is an author of crime fiction novels and although he was promoting the launch of his two new books 'Stanislaw Crossing' and 'Gift of Treason', I wanted to speak to him about his daughter Francesca, who at the age of 12 died as a result of rules, regulations and medical intervention.

As we started the interview he explained that the story he was about to tell me was in two parts and the second part surrounding her death was not to be published just yet. Since our conversation I am now able to share with you both parts to his story.

As we talked I began to realise that there was a beautiful story about the love of a father who dedicated 12 years of his life to caring for his daughter, taking responsibility for her condition which led to a life of quality and intensity that very few people experience.



Francesca was born in 1995 and at her birth something was clearly wrong. Nina, his wife at the time had been born in Norway and at age 8 she went to live in the US. Nina had wanted to complete her education in the UK, and arrived to study her A-Levels before going to university. The key problem was that she had never caught chicken pox. In Norway, like the UK, nearly everyone catches chickenpox in childhood, in the US they vaccinate against it and as Nina failed to catch it in Norway and was never vaccinated in US, she unfortunately caught chickenpox at 14 weeks pregnant.

Francesca was born with a rare condition called Congenital Varicella Syndrome. This is where the virus attacks the foetus. In the US, the syndrome is understood and well documented, however Malcolm finally diagnosed the condition himself using the web just before she died. Congenital Varicella Syndrome is a multiple attack, which acts like a nuclear bomb. The condition attacks muscles in a similar way to polio, because the muscles just don't develop. Bone growth isn't affected but the muscles can't catch up and as a result twists are formed to the skeletal system. Her lungs were compromised, her digestive system was dysfunctional and she had paralysis of the vocal cords which meant her airway didn't open and close. Her body chemistry didn't function so she regularly had drops in her sugar levels, which looked like diabetes but wasn't and her lungs look like cystic fibrosis but it wasn't either.

At the time the health service was organised as internal marketing. This was where they ran as independent services as if it was an independent business. When you have a sick child who needs the skills of a number of hospitals, Malcolm and his wife found themselves waiting for decisions to be made such as 'who was going to pay for ambulance?'. In theory these systems look good on paper but they just don't make sense in real world.

After various trips from St Georges and The Royal Surrey, she was transferred to The Brompton, but still they couldn't work out what was wrong. It was eventually decided that she should go to Great Ormond Street Hospital and were told that the problem with Francesca was that she had some of the symptoms of almost everything but all the symptoms of almost nothing. This made it difficult for doctors to understand her condition and offer any medical solutions.

On being transferred to Great Ormond Street Hospital, doctors eventually managed to diagnosed bilateral palsy and put in tracheotomy, as she was unable to eat she also

had a gastrostomy which created an artificial external opening into the stomach for nutritional support and a feeding tube to provide the nutrition. She came home after 3 months, but after another 2 or 3 months she started to vomit and spent the next 6 weeks back at Great Ormond Street Hospital. Eventually it was agreed that they could take her home and as she was too ill to go to church was christened in their garden. Clearly they were getting nowhere and the doctors decided to withdraw her antibiotics. The general feeling was that if she now caught an infection her body wouldn't cope and she would die, it appeared the medical staff had given up all hope.

However Malcolm and Nina decided to take matters into their own hands and they made an appointment for Francesca to see a Homeopath. Malcolm has a pragmatic approach to medicine of all kinds, whether it be folk

**"If it works,
I'll use it"**

medicine, drug medicine, or complementary therapy, he says *"If it works I'll use it."*

Nina took her to see a Homeopath, and he took one look at her and said she was starving to death. He asked if they could get something into her, such as lentils. Malcolm remembers rushing off to supermarket, coming home to cook the lentils, which he decided to puree and added olive oil to make a good paste. He found one of the syringes, which he used for injecting medications into the feeding tube. Then he substituted the medication for the lentils. Within 24 hours she had improved and after 2 weeks she was clearly better. Although some of the doctors were not happy about Malcolm's new methods of feeding her, eventually one of the doctors agreed to let him carry on, this was a licence for Malcolm and Nina to try new things.

Francesca, it appears was the longest survivor in the world and he believed she would have gone on for many more years.

Over the years they went through so many difficulties, and obstacles, however through discussion with the doctors they usually resolved the situation, and eventually became a team working

together to understand Francesca's complex case.

They over came all her digestive problems, but then after about 18 months she started to have diarrhoea. Malcolm had to start thinking all over again. He said to Nina "I'm beginning to think that as we are bypassing the start of the digestive system, maybe this is causing the problem." Malcolm began to realise that you can try something new for a while, but then it starts to cause another problem, it can have an accumulative effect over time.

That night they were having dinner and Francesca was sitting on Nina's lap opposite him. He noticed that every time Nina took a mouthful of food, Francesca's eyes followed. It was obvious that she was hungry. Malcolm



picked up a little mustard spoon which he dipped in the gravy and as she tasted the food her eyes lit up, this was the first time she had ever tasted food. The next day he started to feed her by mouth and even managed a bowl of Rice Krispies. Although it was hard getting the food into her mouth, they were thrilled that this time there was no diarrhoea. He tried her again with her usual method of feeding and again she suffered with diarrhoea. This was how Malcolm tried and tested new methods and he realised that his theory had been correct and that finally they had started her digestive system. They kept the feeding tube until she was 6 as it was a useful tool for adding medicine, but she progressed well.

When Malcolm researched her illness many years later he found no record of any of these children with Congenital Varicella Syndrome surviving. He found no articles about treatment and his research provided no medical documents or articles on this condition. Francesca, it appears was the longest survivor in the world and he believed she would have gone on for many more years. He understands that she would never have had a long life as her body was under enormous stress trying to cope with its deficiencies. Her body was working all the time and would have eventually worn itself out, so he thinks she may have only survived into her 20's.

Malcolm continued to care for Francesca full time and when they moved house, they were advised that they needed to change all their existing medical connections. As a result they had a new set up. The penny didn't drop at this stage; they didn't really need doctors at this point, she had just had a big MOT at Great Ormond Street Hospital and while her medical records would have frightened most parents,

'New procedures' and 'good practice' that have no place in the real world.

Malcolm had learnt to understand the workings of his daughter's body *"She was like a ship, her hull was taking water, but her pumps were sufficient to keep her afloat, although she was low in the water line, she wasn't sinking any further."*

He devised a treatment program with physiotherapy and created a life for himself and Francesca. "You have a different perception of life because as a carer you start to take on their perception of their life and find pleasure and clarity because you have no time for anything that isn't real or doesn't work. Things like 'good practice' or 'follow the procedure' become absurd as they don't have any actual reality in the issue involved."

Malcolm had a very good GP and most of the time

he managed to care for his daughter, he always had a stock of antibiotics, which he knew what, how and when to use.

When she was rushed into hospital in May 2007 medical staff wanted to treat her with an aggressive use of IV antibiotics and oxygen therapy.

Malcolm and Nina objected. A week later they were summoned to a meeting where they were confronted by a social worker, police officer and medical staff.

They were informed that unless they allowed the hospital to treat Francesca with IV antibiotics she would be made the subject of an immediate police protection order.

Within five months Francesca passed away following respiratory failure, and Malcolm believes her death would not have happened if he had been allowed to continue looking after her.

Malcolm had dedicated 12 years of his life to caring and understanding his daughter's symptoms. Between them Francesca and Malcolm had formed a bond, had taken responsibility for her care and prolonged her life with a quality that the medical profession were unable to offer her.

So it seems sad that those without detailed and 'real' knowledge of the situation could make and enforce decisions that in theory should work but in practice turn out to be life ending.

I feel honoured to have met a man who was willing to put his career on hold, to take on the care and responsibility for supporting his daughter through what must have been at times, lonely and frustrating. Francesca's life may have been cut short but I am sure that in her brief life she experienced an amazing bond with her father that many of us will never experience in our own lifetime.